

**ETHICAL PROCESS FOR GOVERNING PARENTAL USE OF  
GERMLINE GENOME EDITING**

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## **Abstract**

The enormous potential of germline genome editing (GGE) when it comes to eliminating fatal diseases makes its widespread availability all but a certainty. As such, an ethical process to help assuage concerns about permanently altering the course of human evolution is needed. Part of this process should focus on parents, since parents will be making the decision whether to use the technology on their children. The medical community or government would be responsible for approving the use of GGE, so it is their duty to educate and counsel parents. This paper proposes a process built on three steps: education, psychological evaluation, and a final reflective period. This would address parents' knowledge gaps and misconceptions and ensure that they are fulfilling their obligations to protect their children's wellbeing.

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## Table of Contents

<u>Abstract</u> .....	ii
<u>Acknowledgments</u> .....	iii
<u>Introduction</u> .....	1
<u>Background on Germline Genome Editing</u> .....	1
<u>Society’s Misperceived Views on Genetics</u> .....	3
<u>Worries that Led to a Moratorium</u> .....	5
<u>Parental Roles and Responsibilities</u> .....	8
<u>Case Scenarios to Showcase Obligations</u> .....	12
<u>Proposed Process</u> .....	16
<u>Other Ethical Considerations</u> .....	18
<u>Future Implications</u> .....	19
<u>References</u> .....	21

## **Introduction**

Our society holds a cursory understanding of genes, one which is too often clouded by ideas of using one's genetic advantage to create opportunities and better lives for ourselves. These ideas are largely propagated by our wishful thinking and to a smaller extent by companies and clinics looking to gain business. Considering emerging biotechnologies such as germline genome editing (GGE) that can alter a person's genome, there is a worry that misperceived notions of genes and the marketing of this technology will lead to long-term issues, such as deepening socioeconomic divides and harmful, permanent change to our genes. Accordingly, we need to put processes in place that allow progress with new medical technologies while limiting short and long-term consequences to society. I argue here that one such process is a counseling process that parents must undergo before being allowed to make use of GGE. The process would consist of three parts: education, psychological evaluation, and a final reflective step before parents decide if they want to pursue GGE. This would address parents' knowledge gaps and misconceptions, and ensure that are fulfilling their obligations to protect their children's wellbeing.

## **Background on Germline Genome Editing**

Human germline genome editing has emerged as a hot field in genetics and has given rise to many promising biotechnologies—the most prominent being CRISPR/Cas 9 (Ayanoğlu, Elçin, & Elçin, 2020). Germline genome editing refers to a technique where intentional changes to the genome of germ cells is made. When GGE is used on embryos, the process results in a heritable genetic modification, which means that any alteration made would affect every cell of the embryo and would be passed to all future generations (Greely, 2019). As a result, this technology has the ability to change the trajectory of human evolution since it could give rise to generations

with no fatal heritable diseases. Not only could we unknowingly rid our species of useful genes, since any trait can be changed, it could lead to “designer babies” ([Lemonick, 1999](#)). The prospect of choosing your baby’s eye color, intelligence potential, and healthiness is mesmerizing, but snipping away genes when we do not fully understand their interrelationship with other genes could have drastic consequences, like losing protection from diseases yet unknown to us. The consequences of gene editing will not be sudden, but in time, as the quality of the technology improves, GGE will likely be able to select for more genes and be more specific about which are removed. For instance, the first people undergoing GGE will probably do so in order to eradicate chronic and fatal disease. However, with improvements in the technique and our scientific understanding of what each gene controls, future generations could undergo the procedure as a way to alter traits, like eye color, intelligence, and height. Assuming any kind of progress in GGE, we open the door to babies by design. The very idea of being able to create a person according to the parents’ wishes has been a fantasy best left to the future, but with emerging technologies now being more precise, more efficient, and less expensive, the future could be here sooner than expected.

In November 2018, a fantasy became reality when the first genetically edited babies, twin girls, were born. Biophysicist, Dr. He Jiankui, inserted a disabled CCR5delta32 variant into the babies’ genome to protect them against HIV ([Greely, 2019](#)). Dr. Jiankui’s intrepid actions led to global shock and uproar at the use of GGE technology for reproductive purposes, leading to an equally controversial moratorium in the field. Understandably, millions were worried that through alteration of the human germline, science could rewrite the gene pool of future generations. However, not all researchers are on board with a moratorium, despite the potential dangers of the technology. For example, Russian scientist Dr. Denis Rebrikov has started

experimentally editing the GJB2 gene to alter deafness in the germline. He has been quoted saying, “I can see the billboard now: You Choose: a Hyundai Solaris or a Super-Child?” (Cyranoski, 2019) (Regalado, 2020). Underneath his remarks lies the idea that society has already started down a slippery slope in its quest to enhance the human race. There are worries that we will make a mistake, and since genes are heritable, it will result in a potentially catastrophic change to the future of humanity. If we take gene editing to be a means of unstoppable potential, which this paper stipulates, then it is best to accept the move forward, under certain conditions. While it is possible that one day harmful heritable diseases like Alzheimer’s could be eliminated with GGE, what about diseases such as diabetes, where one’s environment plays a great role in its presentation? Moreover, is it known which diseases exist strictly because of genetics? Would the process of eliminating diseases through gene editing need to be accompanied by certain behavioral changes on the patient’s part? Questions like these highlight why it is important to weigh the utility of human germline editing for purposes of disease prevention against the responsibility we have for our own behavior.

### **Society’s Misperceptions of Genetics**

Genes are heavily intertwined with our environment and play a yet unspecified role in mediating pathways between behaviors and risk. As such, behavioral models have difficulty predicting whether behavior will cause a gene to manifest itself in a phenotype. In short, the role of genetics is complicated and nuanced, resulting in potential misunderstandings. We can safely say that genes are made up of DNA and are the basic unit of inheritance. Genes are passed from parents to offspring, containing the information needed to specify traits and disease risk. On this much there is scientific consensus, but it is also where the average person’s knowledge of genes stops. In fact, studies have suggested that most members of society do not understand basic

concepts of genetics, such as disease risk and the recessive-dominant relationship that describes parents passing on their genes to their offspring (Klitzman, 2010). Accordingly, it can be inferred from these studies that many people do not realize that our genetics are far more complex.

As a result of the Human Genome Project, which was completed in 2003, we were able to sequence the more than 3 billion base pairs that make up the genetic blueprint for a human being. The importance and revolutionary aspect of this project was propelled by the belief that the genome holds the key to explaining everything about the human body (Collins & Fink, 1995). Sequencing the genome led to a new era of discovering “genes for” particular diseases, disorders, and traits. This genetic research has brought great scientific knowledge, such as the finding that debilitating diseases like schizophrenia are only 10% heritable. However, this knowledge is accompanied by several misconceptions.

There are three common misconceptions in genetics (Mills Shaw, K. R., Van Horne, K., Zhang, H., & Boughman, J., 2008). One is that our genes are unchangeable. While it is true that our genes cannot change, we can minimize their impact on our health through lifestyle changes like diet and exercise. The second misconception is that traits are coded for by single genes. Some single traits are coded for by thousands of genes. Therefore, we may be only getting a partial look at the big picture if we were to get rid of one “malignant” gene without fully understanding its influence on other genes. Finally, a common misconception is that genetic testing is as good as or a replacement for doctor’s visits and counseling.

Genetic testing companies such as 23andMe achieved success, in part, by enabling customers to learn about their genetic heritage. In the process, the company implies that genes are in a large part responsible for one’s ancestry, current behavior, and physiology (23andMe, n.d.). Other companies such as Map My Gene exacerbate misconceptions further by advertising



genes as the “tell-all” for children. Companies market promises of “Happier Parent Child Relationships” and “Give Your Child a Real Head Start” to take advantage of a parent’s desire to give their child the best opportunities in life (Inborn Talent Gene Test, n.d.). The companies are useful in showing some insight into a person’s biological history, but the technology is not yet able to make exact judgements about undiagnosed medical issues, much less tell all there is to tell about a person’s history, present, or future. Some companies use genotyping instead of sequencing for the testing, which is less accurate. To their credit, 23andMe state this limitation on their website, and people need to know this so that they do not use these services to advocate for GGE (23andMe, n.d.). Businesses are, unknowingly or not, reinforcing the misperception that a person’s characteristics and behaviors are entirely or primarily based on their genetic make-up.

Now that the human genome has been sequenced, there is understandable curiosity and excitement that genes have the answer to all of humanity’s health problems. However, there are several unknowns brought on by such a dominant focus on genetics. Can genes dictate a person’s place in society? Can genes determine a person’s intelligence and therefore their usefulness to society? Our genes have begun to have implications for not only one’s biological identity, but one’s place in society as well.

### **Worries that Led to a Moratorium**

As mentioned above, a GGE moratorium was put in place in order to understand its effects. Technology often races ahead of ethics and the policies meant to govern it. Acknowledging the gap in understanding about genetics in general, and technologies such as GGE in particular, has led concerned philosophers, bioethicists, and scientists to develop standards for how GGE should be carried out. Some scholars and experts have said that this technology is simply too dangerous because the risk is high that it will be misused to create

designer babies (Ranisch, 2020). Others have said that doctors, scientists, and politicians should “take care not to surrender to the understandable claims of the parents and allow genome-editing of embryos only in a few well-defined cases that involve the risk of death or of extremely disabling life conditions” (Lavazza, 2019). Both of these show that the gap in understanding of GGE is that only the benefit and short term consequences are emphasized and discussed. While these concerns are understandable, the two perspectives ignore the middle ground of cases outside of the extremely severe or low health risk criteria. Middle ground diseases like heart disease and gastrointestinal disease may not be immediately lethal, but they can negatively impact quality of life. Current research has seen advancements in treatment for the aforementioned types of diseases, so it makes sense to allow GGE for the sake of eliminating not-so lethal illnesses if the practice can be properly regulated.

Analysis of American opinions towards gene editing for embryos depends on the use and the intended purpose (NW, 2016). A majority of the public supports the idea of using GGE in order to remove disease leading to direct health benefits for the future child. Surveys also reveal that the general public has concerns about using GGE to create the perfect child, e.g., with increased intelligence (NW, 2016). In general, Americans feel that editing traits is taking the technology too far but that eliminating risk of disease is an acceptable use of gene editing.

However, it is ethically challenging to decide what diseases are worthy of GGE. How would one classify which diseases justify the use of GGE? It is difficult to imagine anyone opposing the eradication of various hereditary diseases like Huntington’s disease, cystic fibrosis, muscular dystrophy, or sickle cell, ones that negatively impact one’s quality of life and impose significant costs to the health care system. Yet there is some degree of uncertainty as to the environmental factors influencing the severity of sickle cell, despite genetic studies. We run the

risk of under-representing the importance of social factors on the experience of disease, including the role of the parent and environment in their child's development. Researchers have found that climate, air quality, socio-economic circumstances and exercise may all play a role in the severity of sickle cell disease (Tewari, Brousse, Piel, Menzel, & Rees, 2015). If GGE were to become the go-to solution for all severe ailments without proper consideration of the role of the parent and society as a whole, then other important contributing factors for a disease go ignored. By eliminating harmful genes based on our current, limited information, we may be able to eliminate a disease, but we also remove our ability to further research how that gene interacted with other genetic and environmental factors. What if a malignant gene we took out a decade ago proved to be responsible for controlling a beneficial gene that was just discovered? One of the reasons behind the hesitation towards GGE is that humanity might accidentally delete a useful gene. To prevent this from happening, it falls on the scientific community to educate society about what genetics research is conducted and what the results tell us that genes can and cannot do. And it falls on parents to understand that there will always be some uncertainty that comes with GGE.

Another reason behind the GGE moratorium is that parents might make decisions for their future children that will cause a strain on the parent-child relationship. That is, a child could grow to resent the GGE-related choices made or not made by their parents. This points to the need to examine the role and duties of parents, to which I turn next. This paper will present case scenarios that highlight the misconceptions parents can have and interpersonal issues that can arise in the parent-child relationship around the use of GGE. They highlight the importance of placing knowledge about the limitations of and consequences of GGE at the hands of the parent so that they can make more informed decisions.

## Parental Roles and Responsibilities

The role of the parent in determining the ethical use of GGE needs be explored; namely, what are parents' duties to their children? Duties encompass both moral and legal obligations. Legal duties are well-established. When a child is born, parents are legally obligated to provide food, clothing, shelter, medical care, and education (Review, n.d.). By contrast, there is less agreement about parents' ethical obligations. There are arguments based on the best interest standard (BIS), which is often applied to parents when they are making decisions for their children. The BIS implies that people who care for others will do so in good faith by placing that person's best interests above their own (Kopelman, 2013). It has been described as "the option that maximizes the person's overall good and minimizes the person's overall risks of harm" (Rhodes & Holzman, 2014). However, there is a vagueness as to the ethical duties or obligations that parents have in acting in the best interests of their child. Using the BIS model for GGE would highlight the subjective and polarizing nature of "what the best interest" truly is. Under the lens of the BIS, parents would be defining "best interests" as 'providing their child the health necessary to be open to all opportunities.' For instance, a child should not have to rule out a career as a flight attendant because they are too short or a pilot because they are at risk of Huntington's disease. GGE would provide these opportunities.

The Nuffield Council of Bioethics developed a report that states that GGE would be allowed if it met the following principle (Nuffield Council on Bioethics, 2018):

*Principle 1: The 'welfare of the future person'*

*Gametes or embryos that have been subject to genome editing procedures (or that are derived from cells that have been subject to such procedures) should be used only where the procedure is carried out in a manner and for a purpose that is intended to secure the welfare of*

*and is consistent with the welfare of a person who may be born as a consequence of treatment using those cells.*

Like the BIS, this principle is vague in terms of defining what the welfare of a person is and how it can be assessed. As such, we need to establish agreement on what parents owe their children. If we, as a society, look at the intention behind the use of a technology like GGE before we are faced with the unintended consequences, then we can minimize the chance that a wrong decision is made.

When would-be parents think about their future child, they tend to make predictions about how their life will turn out based on the parent's own genetic makeup, experiences and beliefs. But parents tend to be open to the unforeseen choices their children might make, such as a child who pursues interests far different than those of their parents. GGE gives parents a choice to minimize the chance of undesirable outcomes, i.e., disease and traits, but in doing so, the parents may develop heightened expectations. There is literature on how parents have high expectations for in vitro fertilization (IVF) babies and how those high expectations affect the child's psychosocial development (Anderson, K. N., Rueter, M. A., Connor, J. J., Chen, M., & Damario, M., 2015). Thus, it is reasonable to assume that this would also be the case with GGE. Parenting requires acceptance. We do not own our children and our children do not exist simply for our fulfillment. Therefore, we should focus on the duties of the parents to promote the wellbeing of children, and not just the parents' own wishes about their children. I propose that adequately focusing on the wellbeing of their future child requires prospective parents to meet three ethical obligations: respect the child's autonomy, honor their right to be loved, and uphold the duty to shape them with care.

Child autonomy: Prospective parents have an obligation to realize that their future child is a unique individual, not simply a miniature version of themselves or, as GGE would allow, a reflection of how they want their children to be. There is a difference between hoping your child turns out a certain way or has certain opportunities and actually performing GGE, which has consequences that are still unknown. Thus, parents have to reflect, is it really worth it in their particular case, or should it be left to people who really need it right now? The Universal Declaration of Human Rights in 1948 states that “all human beings are born free and equal in dignity and rights” (United Nations, 1948). Children are born with an ethical right to an “open future” (Feinberg, 1980), which protects the future child against having important life choices determined by others before they have the ability to make them for themselves (Feinberg, 1980). The right to an open future implies that children “possess ‘anticipatory autonomy rights’ that are violated when a child's opportunities in life are limited” (Feinberg, 1980). Furthermore, in the United States Declaration of Independence, it states that people have certain unalienable rights that include life, liberty, and the pursuit of happiness (Jefferson, 1776). Future children should be free to choose what brings them happiness since they are individuals in their own standing. Thus, a child does have autonomy and that right needs to be acknowledged by parents, so they do not impose themselves and their image onto their child.

Right to be loved: Philosopher Matthew Liao has argued that there are certain fundamental conditions for human beings to pursue a good life; one of them is the right to be loved (Liao, 2015). He shows that by loving a child, parents keep intact the parent-child relationship and strengthens it through the human connectedness and flourishing of both parties involved. When parents choose to procreate, they have an inherent responsibility to take care of the child, but some aspects of this care are not enforceable. Parents should but are not legally

required to love their children. With the use of GGE, it is not the case that the child is suddenly unlovable. It is more that the parent is taking somewhat of “short cut” by doing GGE. GGE will provide the child with more opportunities, etc., but it also can be perceived as taking some of that responsibility off the parents. Parents, thus, might not rely on love too much to get their child through life and be neglectful and absentee damaging their parent-child relationship. Nonetheless, it is in both parties’ best interest to love their children since they represent the next generation of thinkers and doers.

Duty to shape the child with care: There is a wealth of data supporting the fact that parental discipline, monitoring, shaping, warmth, and responsiveness are all contributing factors to how children will grow up and adjust in society (Kiff, Lengua, & Zalewski, 2011). How one shapes a child with care depends heavily on the style of parenting. It includes being empathetic and sympathetic towards the future child in a specific respect. This is different than loving a child since a parent could love a child, but fail to show empathy with a specific experience that the child has. Parents considering GGE should show an emotional understanding of what their child would experience with and without the procedure. While it is difficult to truly understand an experience, one has not gone through oneself, one can demonstrate the willingness to learn and discover hitherto unknown human experiences and emotions. Only after compassionate and curious thinking would prospective parents fully understand the consequences of which genes they have chosen to modify. Through parenting and the environment, children develop skills, self-regulation, morality, and identity. A child’s genes and style of parenting affect one another and the outcome of the child’s outcome (Maccoby, 2000). Thus, the “perfect child,” which is what is assumed to be the goal/result of GGE, still needs to be shaped and parented with care.

Overall, prospective parents need to promote their future child's individual wellbeing over their own, and be responsive to any of the child's needs, expected or not. In doing so, the parents would honor the inherent human dignity and autonomy of their child, including respecting their physical integrity, acknowledging their individuality, having their voice and choices taken seriously, and offering them fair opportunities (Basser, 2011). Ethical obligations would encourage and facilitate prospective parents to acknowledge what they owe to their future children.

### **Case Scenarios to Demonstrate Obligations**

In what follows, I will use case-based reasoning to demonstrate two ways in which misunderstanding the scope of genetics can be problematic for parental decision making about reproduction. I will not consider all factors that are ethically relevant to decisions about GGE, such as the systemic injustices in our society. Nonetheless, the two hypotheticals I analyze will represent typical cases that fertility clinics will likely face when GGE technology becomes available. The cases will illustrate the need for a process as a means of acknowledging and evaluating a parent's ethical duties to children.

#### Case #1:

*A 33-year-old woman named April has a family history of early-onset breast and ovarian cancer. She wants to eliminate the possibility of transmitting this condition to future generations. April has undergone a genetic analysis that has identified a mutation in the BRCA1 gene. She has not yet had a diagnosis of cancer but is aware that, to reduce her risk of getting cancer, she could have a double mastectomy and have her ovaries removed. Knowing the emotional toll, the cancer can carry due to caring for her family members, April has decided she does not want her child to experience the illness that she has seen members of her family endure. In addition, she*



*does not want to be a parent to a child who could have cancer. Therefore, when April and her partner decide to start a family, they go to a fertility clinic in hopes of using CRISPR to modify the mutation in the BRCA1 gene. April could choose preimplantation genetic testing, PGD, where embryos are analyzed before they are transferred. This would ensure that only the embryos without BRCA1 are implanted into the womb. However, PGD is only selecting unaffected embryos and that is not good enough for April. Although on average, half of her embryos will not bear the mutation without GGE (as only one of her two chromosomes carry the mutation), maximizing her number of embryos is a priority. Hence, April's desire is to correct the mutation-bearing embryos. She wants to ensure only embryos without the mutation in the BRCA1 gene are implanted since she does not want to risk a child developing breast or ovarian cancer in the future.*

*The doctor at the clinic informed April and her partner that a mutation on the BRCA1 gene increases the risk of developing cancer but he did not emphasize that cancer could still develop due to other major factors. Thus, April was confident in her decision in using CRISPR in order to have a baby because the baby would be cancer free, which is her only intention.*

In this case, April has seen what breast and ovarian cancer have done to her family and has personally experienced the effects of carrying the BRCA1 gene. She simply cannot tolerate the emotional weight of cancer anymore and does not want her future child to have to go through a similar experience. Thus, her justification for using CRISPR is to enable her child to live a life without developing breast or ovarian cancer. However, this edit does not guarantee that the child is protected from developing breast or ovarian cancer in the future. (April does not understand that editing out the gene is not 100% effective). Editing the BRCA1 gene does not eliminate the risk of cancer completely, since there are environmental factors such as diet, chemical exposure,

and aging that can contribute to the development of cancer. In fact, the overwhelming majority of breast cancer is not inherited, it is sporadic.

As mentioned earlier, society does not understand the role of genes in the nature versus nurture problem—how genetics and the environment play a key role in the health of an individual. Thus, April may not understand that her child can develop breast or ovarian cancer in the future. She is set on protecting her child from being exposed to cancer as she was.

April is entering a parent-child relationship with the expectation that she will not have to handle cancer again. By only implanting embryos with edited BRCA1 genes, she is reassured that that will not happen. However, what will April do if her child develops cancer? By her own assessment, she will not be able to face that situation mentally or emotionally. There is a worry that she would not properly accept a child with an increased risk of developing cancer or care for them as a parent should. In order to be able to love her child no matter what, maybe April should have taken a step back and thought about whether she wants to have a child if cancer is always a possibility. By appreciating her ethical obligations to her future child, April would be better able to accept her child as they are, and cultivate a parent-child relationship that would secure the wellbeing and fulfill the needs of the future child.

Case #2:

*A 25-year old African American woman named Jenny and her husband John recently found out that they are having a baby. Jenny and John both come from large military families; they joined the Army right out of high school, much to the pride of their grandparents who served in Vietnam. However, John's family is known to carry markers for sickle cell and colorblindness, factors which have prevented some of his family members from enlisting.*

*John grew up seeing how his grandfather treated his father as inferior and lesser-than because of his inability to serve, and he does not want that future for his son. Jenny and John agree that they should go to a fertility clinic to get pregnant through IVF. This way, they can use CRISPR as a means of ensuring that their baby can grow up healthy and be able to serve. They will only implant the embryos that have edited out the markers for color blindness or sickle cell, diseases that would disqualify the baby from future service.*

The couple wants their child to have a fair and equal opportunity to serve in the military, like any other healthy person. The question is whether Jenny and John are prepared to love a child who does not want to join the military. If Jenny and John understood the ethical obligation to treat their child as a unique individual with autonomy, they would see that it is up to their future child to decide if the military is something they want to pursue. On the other hand, what if, in the future, John and Jenny's child **does** want to enter the military but cannot do so because of gastrointestinal or endocrine conditions caused by their diet? In honoring their ethical obligation to nurture their child in a caring manner, and assuming that enlisting in the military is their child's goal, John and Jenny would need to do more than just remove markers of sickle cell or colorblindness. They would need to play a bigger role in shaping their child's nutritional habits. Furthermore, realizing that their child has a right to be loved no matter what should factor into their decision to become parents at all. It would help Jenny and John to see that their family's opinion of their future child's path does not matter and should not be a large factor in deciding what kind of child they want. As in the first case, acknowledging the prospective parents' ethical obligations would help foster a better parent-child relationship for Jenny and John if they decide to undergo GGE for reproductive purposes. What is more, the parents would have a better

understanding of the limitations of GGE, especially when weighed against all of the possible long-term dangers of the technique.

### **Proposed Process**

We, as a society, already distinguish people by the type of parent they are – biological, foster, or adoptive. For the latter two, society has a system in place to evaluate the people who want a child who is not biologically related to them. The act of choosing a child and wanting to specifically be a parent to an adopted or foster child, calls for an evaluation and process by the state. Society wants to ensure that children in need of parents or a home are taken care of in ways that secure their wellbeing. They require an extensive check of the prospective parents' intentions and require them to recognize their responsibility to the child. This is to make certain that the parents are a good fit to parent an adoptive or foster child. A similar process should be applied to parents who choose to undergo GGE since they want to specifically be parents to a genetically edited child. Parents who consider GGE should be made aware of the tragedies committed under the banner of eugenics, such as the Nazi's goal of ensuring the purification of the Aryan race. They should be made aware of the potential for discrimination that could arise from being edited versus naturally-born. Plus, the elimination of genes for the sake of disease might be a good goal in the short term, but in the long term it is not a good idea to remove genes without knowing the consequences. For instance, removing the sickle cell trait might get rid of the disease, but the protective mechanism against malaria might result in more harm than good. Parents should be made aware of why there should be limitations on the use of GGE.

Simply establishing the ethical duties parents have to their children is not enough. There needs to be an ethical process in place that focuses on the education and evaluation of parents who want a genetically edited child. I propose that a process of mandatory counselling be

implemented before parents are allowed to make use of GGE. It is a way of reducing possible harms from gene editing that arise because of parents' misconceptions or a lack of self-reflection. The process would consist of three parts: education, psychological counseling, and a final reflective step before deciding. First, prospective parents who have the opportunity of GGE should be seen by a genetic counsellor who can educate them on what editing of the germline of their future child would entail (Dumont-Driscoll, 2002). Parents would need to understand that by just deleting or editing a gene in the hopes of eliminating a disease does not guarantee that their child will be free of disease. The genetic counsellor would be able to provide the knowledge and guidance on the specific medical and biological facts that the parents would need.

After meeting with the genetic counsellor, the second step would involve seeing a psychologist to explore with the parents their true intentions and what it means to parent a genetically edited child. The prospective parents would have already gained knowledge of the nuances of what could happen biologically with GGE. Now, the psychologist will help them understand if they can meet all the ethical obligations that parents have to their children. Through the counselling, parents would be able to affirm whether their future parent-child relationship will be filled with trust, support, intimacy, and care or whether it will be clouded by preexisting intentions, feelings, values, and norms (Schües & Rehmann-Sutter, 2013).

Lastly, the genetic counsellor and the psychologist will meet, compile a report and discuss their thoughts and recommendations. They will present a consensus view to the fertility clinic and the prospective parents. In light of the underlying risk of altering the path of human evolution, there should be a larger societal process of determining which genes can be edited at all, and then if parents want to edit those particular genes of their embryo, then they have to go

through the process outlined here. Evaluating the decision-making process may help the parents to gain a better prospective and insight into their decision to want GGE before they proceed. If the parents demonstrate a full understanding the scope of GGE in both a biological and environmental sense, they should be allowed to pursue the procedure. The goal is not to prevent people from becoming parents. It is to prevent GGE use from escalating out of control, at least until we know some of the long-term effects.

Employing this counselling process in the two cases presented above could have helped April and her husband as well as Jenny and John to truly understand what it would entail to have a genetically edited baby and their true feelings toward the future child. When their child is here and grows, anything can happen due to the interplay of genes and the environment. If April truly understood this, maybe she would have changed her view on her future child. She would not have had the heightened expectation of a cancer free child and be able to love and nurture her child if they do get diagnosed with cancer. If John and Jenny knew their true intentions well, maybe they would have decided on not undergoing GGE for a baby for the sole purpose of their future child serving in the military. I understand the proposed obligations and process are not perfect, but they could reduce the risks I have identified.

### **Other Ethical Considerations**

Establishment of such a process will generate and have to address justice challenges, since access to human germline editing technology will be governed by the ability to pay. Money largely determines a person's standing in society; when people have money, more resources and opportunities arise. New technology is often expensive before it becomes widely adopted, so not everyone would have access to it. Those with the financial means will be given the opportunity to widen their considerable advantage over those who cannot afford the procedure. That is, the

well-off could eventually choose to have healthier and more intelligent babies, effectively perpetuating inequality. While this is a justice issue, I do not believe that the ability to pay should be the only ethical consideration governing GGE. The long-term consequences of removing or modifying genes on a global scale may create and exacerbate the inequalities that are bound to arise when those who can afford the procedure are able to eliminate disabilities or enhance health through editing.

Another ethically relevant question to consider is the way in which GGE differs from other types of reproductive technology such as IVF. I believe that it is permissible to legally govern the right to parent a genetically edited child since it involves an irreversible decision whose consequences most people do not understand. Genetically editing the genes of a baby carries consequences that are not seen in IVF babies. In IVF, fertilization between eggs and sperm is done in a lab, where the embryo is allowed to grow before being transplanted into the womb. Allowing parents to use GGE serves their evolutionary drive to want the best for their child by placing the decision to edit in their hands. To do so in an ethically responsible way, parents should be made aware of the impact of germline editing, such as the creation of new inequalities and eugenics, and be clear about their own intentions before using the technology.

### **Importance & Future Implications**

When GGE hits the market in any capacity, the forces of capitalism will result in increasing demand due to its unique usefulness. Soon, there will be competitors and thus massive pressure to undergo GGE. With time, it will be increasingly difficult to have discussions about what are the reasonable expectations of gene editing and to what extent a parent's reasoning is the basis for making life-altering decisions about their child's health. Perhaps the parent believes that some of the responsibility falls on the medical community to not move forward with any

procedures that may cause unknown or unintended consequences. In that case, an ethical process would serve as a compromise between the two parties. The medical community agrees to offer procedures that have greatly minimized the potential risks with the understanding that a parent is to not abuse genetic editing. As it stands now, the public's knowledge about genes leaves a lot to be desired, so a more educated population would be the logical first step to welcoming many members of society into the discussion surrounding GGE.

I focused on the obligations of parents in the context of GGE. This paper makes no claims about who should and should not be a parent. It is about how informed they and society should be when making GGE decisions because those decisions and eventual trends can have global and long-term consequences. This is just one part of the necessary governance of GGE. By articulating parents' obligations to their future children and proposing a process by which GGE could be regulated, we can next address what the duty of a physician is in governing and employing GGE. Also, what obligations do the technician or clinic performing the GGE have to respect the prospective parents' or future baby's interests? Then we need to consider broader questions of how international regulation can be achieved and what duty the global community has in regulating GGE so as to avoid exacerbating systemic inequalities further. Though an ethically adequate process for implementing GGE will need to be comprehensive, the process outline here for protecting the parent-child relationship is a starting point.

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